Advance Directives for Health Care and Financial Decision-Making

Early Stages of Dementia

Goal

- **Person and caregivers understand advance directive options and their purposes, and plan accordingly**
- **Person articulates wishes concerning future health care, end-of-life issues and financial decision-making to the appropriate people**
- **Person executes advance directives as permitted legally according to cognitive status**

Key Assessment Issues	Possible Interventions
Person • Person may not be aware of options or importance of advance directives • May be reluctant to discuss issues • May not understand consequences of not planning ahead • May become confused/overwhelmed with how to complete the advanced directive forms • May not feel able to evaluate the options without assistance and support • May not be aware of possibility of brain donation and it's importance • Person's judgement may be somewhat impaired.	Person • Educate person about advanced directive options and importance of addressing them during this early stage of the disease (may need to leave some materials for review first) • Provide and use materials and list of questions to facilitate discussion of decision-items (*see references on page 6.4) • Discuss consequences in terms of having to have a guardian appointed, costs and difficulties in guardianship, restrictions on guardian decision making compared to person making decisions now, etc. • Assist in completing advance directive documents, if appropriate for Care Manager to do so (or refer for assistance to appropriate person/agency) • Offer to facilitate family meeting to discuss person's wishes • Refer to the local Alzheimer's Association for assistance • Encourage person to include discussion of autopsy between physician and family during the course of decision making • Encourage person to be re/evaluated for a diagnosis and competency
Caregivers/Family and Friends • Caregiver(s), family and friends may be reluctant to discuss issues • Caregiver(s) may be unaware of consequences (to them and the person) of person not executing advanced directives • Caregiver(s) may be uncomfortable in decision-making role related to advance directives • Caregiver(s) may not feel able to evaluate the options without assistance and support	Caregivers/Family and Friends • Provide materials/questions and information on consequences of not executing advanced directives to family for their review and consideration, then follow up for discussion later • Educate family about advanced directive options and importance of addressing them during this early stage of the disease • Facilitate family meeting to discuss person's wishes if desired by patient and only with family members approved by him/her • Refer to Guardianship Support Center for legal information about advance directives (*see page 6.4) • Refer to legal counsel if complex issues • Refer to the local Alzheimer's Association for assistance

Advance Directives for Health Care and Financial Decision-Making

Early Stages of Dementia (continued)

Goal

- **Person and caregivers understand advance directive options and their purposes, and plan accordingly**
- **Person articulates wishes concerning future health care, end-of-life issues and financial decision-making to the appropriate people**
- **Person executes advance directives as permitted legally according to cognitive status**

Key Assessment Issues	Possible Interventions
Caregivers/Family and Friends • Other family members may have – or try to exert - influence over person and his/her choices – positively or negatively • Caregiver may not be right person to serve as later decision-maker (e.g., potential conflicts of interest, own decline or health issues, not able to see person's needs because caregiver is "too close" - sees person too frequently to notice slow decline in function, etc.)	Caregivers/Family and Friends • Refer to legal counsel if complex issues • To avoid later challenge, document in medical record that lawyer, social worker and/or physician are confident that person had sufficient capacity to execute document(s)
Caregiver/Agent • May not know about extent of distributing copies of advanced directives • Alternate may not be as involved in communication as agent is	Caregiver/Agent • Assist in making and sending copies of health care document(s) to physician, clinic, other providers, agent and alternate; and assist in sending copies of financial document(s) to financial institution, providers, agent and alternate • Assure wallet card indicating individual has a health care advance directive is completed and person has been assisted to place card in wallet (and bracelet is worn if DNR status) • Encourage discussion of all decisions and documents with physician, agent and alternate (also to include alternate in discussion of subsequent changes over time)
Health Care Providers • May not be aware of or remember all decisions made, especially over time • May have multiple providers, all may not be aware of information (e.g., providers who could be caring for the person when an emergency arises – adult day center, home health, etc.)	Health Care Providers • Ask/direct physician to place copies of all documents in person's medical file and file copies with hospital of choice • Provide copies or access to documents to all staff as needed • Encourage physician to do/refer person for a competency evaluation if necessary • Encourage discussion of autopsy between person, physician and family at this time • Encourage providers to include alternate in decisions/updates

Advance Directives for Health Care and Financial Decision-Making

Middle Stages of Dementia

Goal

- **Person executes advance directives as permitted legally according to cognitive status**
- **Ensure that person, if competent, is still comfortable with choices of substitute decision- makers, types of decisions delegated, preferences listed, etc.**
- **Caregivers respect/implement/follow advance directives as permitted legally according to person's cognitive status**

Key Assessment Issues	Possible Interventions
Person • Person may not be competent to complete advance directives if not already in place • Person could possibly be able to participate in executing more limited aspects of advance directives - if not already completed • Person's preferences may have changed, prompting a change in advanced directives • If person's judgement is impaired, she could become confused about wishes, and be at risk for exploitation by others	Person • Encourage competency evaluation to identify aspects of advance directives the person may still be able to determine • Seek guardianship if person is deemed to be incompetent • Provide support to the person and legally appointed individuals as they work through this process, and be available to assist with problem solving • Ensure that previously completed health care documents are in medical file and all physicians and providers are aware of them. • Ensure that previously completed financial documents have been appropriately distributed
Caregiver/Agent • Caregiver/Agent may need to activate Health Care or Financial Power of Attorney (HCPOA/FPOA) • May need to seek guardianship of the person if HCPOA/FPOA not done while person had capacity to do so	Caregiver/Agent • Encourage person and any family members or others desired by person, to discuss the plan to enact advance directives with physician • Activate Health Care and/or Financial Power Of Attorney • Refer to Guardianship Support Center for legal information • Support person and family in the process (*see page 6.4)
Family • Family dynamics may have changed • Family members may not agree on current and future arrangements	Family • Refer to legal counsel if complex issues, conflicts or inadequate documents (e.g., internally conflicting, invalid, don't address decision needing to be made, etc.) • Encourage family meeting with professional facilitator (and/or Ethics Committee if individual is in hospital, nursing home or other institutional setting) to mediate and assure advocacy for person with dementia. Ensure that someone is appointed to speak for person's stated preference if he/she no longer can, i.e., advocacy counsel • Seek guardianship if irreconcilable conflicts
Service Providers • See First Stage information page 6.2	

Advance Directives for Health Care and Financial Decision-Making

Late Stages of Dementia

Goal

- **Person's wishes regarding end-of-life care and financial decision-making are honored**

Key Assessment Issues	Possible Interventions
Caregiver/Agent • Individual appointed as agent under HCPOA may get "cold feet" and be unable to "let go" or honor person's wishes • Documents may be confusing, incomplete, etc., when time has come to honor person's previous wishes for end of life care	Caregiver/Agent • Offer support and /or encourage family to seek support and engage in discussions with trusted confidants regarding the decisions that must be made • Refer for guardianship if document(s) are invalid, inadequate or there are irreconcilable conflicts • Refer to Guardianship Support Center for legal information about advance directives (*see below) • Refer to local Alzheimer's Association Chapter for help
Family • Family conflicts may arise as end-of-life issues are faced • Family may object if autopsy options for final diagnosis and research may not have been discussed earlier, and object to brain donation	Family • Work with family members, physician (and/or Ethics Committee if person is in hospital, nursing home or other institution) to resolve conflicts • Remind family about autopsy planning, or explain brain donation and refer to local Alzheimer's Chapter for information if they don't know about it yet • Refer to legal counsel if complex issues, conflicts or inadequate documents (e.g., internally conflicting, invalid, don't address the decision needing to be made, etc.)
Service Providers • All service providers involved in person's care need to be fully informed of person's end of life wishes	Service Providers • Educate or remind family of need to continually make sure new and/or different providers are informed about the advance directives that have been activated **References:*** **Wisconsin Guardianship Support Center 800-488-2596** **Wisconsin State Bar 800-488-2596** • American Bar Association's Lawyers Tool Kit for Advance Directives **Coalition on Wisconsin Aging Groups 800-728-7788** • 25 questions for advance directive planning